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ABSTRACT

This paper proposes and describes use of a Transition Liaison individual, together with a discharge plan, to facilitate the successful discharge and transition of hospitalized children to the family and community-based services. Increased and more accurate communication between the family and professionals is seen as one of the primary benefits of utilizing a Transition Liaison. The Transition Liaison should be an individual knowledgeable in medical terminology and hospital procedures as well as in community and school services. The Transition Liaison's role would include ensuring compliance with regulations, initiating a discharge plan when a child is admitted to a hospital unit, and updating the plan on an ongoing basis. The Transition Liaison can also help teachers meet the special health needs of the child in the classroom and devise a system to prevent the child's falling behind if rehospitalization is necessary. (Contains 29 references.) (DB)

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Utilizing a Transition Liaison in Discharge Planning

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The composition of the pediatric population in hospitals is far different today than it was a decade ago. As a result of increased medical knowledge and technology, more children are surviving complicated births and life-threatening illnesses. In fact, infants who are hospitalized frequently or for long terms, make up over half the population of hospitalized children (Goldberger, 1988). Added to this increasingly large population are those infants who have been diagnosed at birth as having some type of handicapping condition that require specialized treatment and planning in the hospital before discharge. The capacity of medical science to save the lives of more infants and to extend the lives of chronically ill children has also altered the age distribution of hospitalized patients. There is an increasing proportion of infants and adolescents in pediatric units (Thompson, 1989).

The strictly medical needs of children are adequately addressed by the primary physician. More often than not, infants and children are discharged from the hospital with prescriptions and doctors' orders that are sufficient for their well-being. However, medical prescriptions and orders alone are grossly insufficient for children who have been diagnosed with illnesses which require chronic medical care and future hospitalization, or for infants with, or at-risk for, developmental delays. Once a child is medically stable and the prognosis for continued medical treatment is long-term (whether hospital-based or home-based) discharge planning becomes critical. These infants and children along with their families, need more than prescriptions and the next scheduled appointment; they

need the coordinated efforts of the health care and of community services on their behalf. The authors suggest that a Transition Liaison, knowledgeable in medical terminology and hospital procedures, and in educational community services (e.g., public schools, nurseries and other preschool programs), provide the necessary link between the family and the hospital, the family and community-based services, and the hospital and community-based services.

A discharge plan including a Transition Liaison will also help to implement recently amended federal laws. Federal initiatives, mainly Public Laws (P.L.) 94-142 and 99-457, have now emphasized the need for comprehensive, family-centered, multi-disciplinary, early intervention services for infants and toddlers (Bruder and Walker, 1990). These laws state that it is the child's and the family's right to receive community-based or home-based services if the child is preschool aged. P.L. 99-457, recently renamed the Individuals with Disabilities Education Act (IDEA), specifies that an Individual Family Service Plan (IFSP) must be developed to include the name of the case manager from the profession most immediately relevant to the infant's, toddler's or family's needs. IDEA also specifies that the IFSP include the child's present level of physical development, a statement of the family's strengths and needs, a statement of major outcomes to be achieved, a statement of specific early intervention services needed, projected dates of objectives and the steps to be taken supporting the transition of the handicapped toddler into the next educational setting (Federal Register, 1989). These regulations were developed to increase family participation in the education

and care of their children with special needs. Clinical practice in developmental pediatrics and in other developmental specialties is also moving in the direction of a greater dependence on the family's perspective and a more thorough blending of developmental intervention into infant's play and normal caregiving interactions (Gilkerson, 1990).

No matter what the age of the child, or into which environment he/she will transition after the hospital stay, both the family and the professionals would benefit from coordination of information through a formalized discharge program. Preparing families to be active participants in the transition process and to become informed advocates for their children is integral to transition planning (Kilgo, 1990). Service providers in all areas must come together to coordinate their services in order to maximize the benefits of community care.

The present authors propose a model that takes additional steps to insure that more children receive services mandated by federal legislation and ease parents' and caregivers' burdens as well as assist physicians in developing an increasing awareness of community service providers. This "Discharge Planning Model" (see Figure 1) calls for a Transition Liaison to take the lead in the discharge and planning from the hospital to the home. The role of the Transition Liaison is interdisciplinary in nature: The Transition Liaison needs a working knowledge of medical terminology to better work with hospital staff, a thorough awareness and understanding of community and school services, and empathy for family needs. Initial contacts with hospital staff and school administrators are

made more easily with professionals who have both a medical and social science background (Gilkerson, 1990).

Insert Figure 1 about here

Great strides have been made, and continue to be made in closing the gaps between medical and educational professionals. For example, training programs for pediatricians in child development and handicapping conditions have been initiated, and special articles have been written in pediatric journals that focus on educational objectives (Guralnick, 1981; McInerny, 1984). This new interest in children's education is, in part, a result of Public Law 99-457. This training is especially important because the physician is one of the first people to come in contact with an infant and has the opportunity for identification of special needs. If children are to be identified and if the spirit of Part H is to be fully realized, it is crucial to plan a program of services that fits into the routine service niches utilized by most infants and families (Wenger, et al, 1989). If the physician does not identify a preschooler as needing some type of special education services early, there are few other opportunities for identification until the child fails at school (Goodman and Cecil, 1987).

Medical professionals are somewhat isolated from community-based services; their focus is primarily on the acute, immediate needs of the patient (Gilkerson, 1990). Until now, physicians have been hesitant to refer children for further developmental or neurological evaluations; however, early intervention

effectiveness cannot be adequately addressed if diagnosis is delayed and children are withheld from services during crucial years (Goodman and Cecil, 1987).

Physicians may be less comfortable when they are asked to focus on a full range of characteristics of the child, including skills and talents, rather than only on a special health condition (Stein, 1986). MacPhee (1984) suggests that pediatricians may not receive adequate training in child development or may be reluctant to assure nontraditional responsibilities.

Wysocki, Gujaraj, Rogers and Galey (1987), surveyed residents who were given an opportunity to be educated in developmental disabilities. The survey revealed that the residents gained a greater awareness of community resources available for handicapped children. Their ability to communicate effectively with the teachers about the developmental and educational needs of a handicapped child also increased along with their sensitivity to individual handicapped children. Continued effort must be made on the part of medical schools to educate faculty members and especially heads of pediatric departments, regarding the need for teaching developmental/behavioral issues (Charney, 1989), and on understanding the homes and communities of the children they serve (Kohrman & Diamond, 1986; Richardson, Guralnick & Tupper, 1978). Geik, Gilkerson, and Sponseller (1982) and Gilkerson (1990) have argued for appropriate professional training so that physicians can function as facilitator/consultants, infant specialists, parent educators, team collaborators, and program developers and advocates.

One of the greatest benefits to be gained from a Transition Liaison would be that of increased and more accurate communication. All too frequently miscommunications occur between physicians and parents. Various explanations for miscommunication are possible: time constraints on the part of the physician, lack of knowledge of the medical vocabulary on the part of the parents, or conflicting messages to the parents from different physicians or nurses. Hospital professionals need to look beyond the confines of the hospital room or pediatric unit and be acutely aware of what the families' "life after medicine" is like. The role of a Transition Liaison would address problems of parents who become confused as to who said what to do when; communication between parents and hospital personnel should become clearer and easier. Such communication is a prerequisite to improving cooperation that can be the basis for enhanced services for the child, and the basis of a rewarding collaboration for the involved professionals (Gilkerson, 1990; Stein, 1986). The families and professionals would benefit from the coordination of information and communication through a formal discharge plan (Bruder & Walker, 1990).

Plans for discharge would be initiated by the Transition Liaison as soon as a child is admitted to a hospital unit, and the plan would be updated on a regular basis throughout the hospitalization. When a case management system is not in place, the responsibility of discharge planning can fall on one of many different people including parents, doctors, nurses, social workers, child life specialists, or other therapists/counselors who are already burdened with daily

responsibilities and who may not be fully aware of the range of community services available. Kilgo (1990) recommended an interagency transition plan which would outline the transition activities to take place, specifying timelines, staff responsibilities, mechanisms for coordination with other agencies and evaluation procedures. Here again, the Transition Liaison could provide flexibility in drawing upon developmental specialty areas and the wide range of concerns that families may have about care provision (Long, Katz & Pokorni, 1989).

During the transition from a hospital to the home or community agency, much of the burden will lie on the sending agency (i.e., hospital). Those professionals involved must be certain that the child is healthy and safe when he/she leaves the hospital. They must also be confident that the parents or the receiving agency is capable in providing the specialized care needed to maintain the child's healthy status. Once accomplished, a portion of the responsibility must shift from the sending agency to the parents or community agency such as the public school systems.

The changes and added stresses that are typically encountered by children and families making the transition from hospital to home, even with early intervention services, require an increased focus on the family in the transition process (Kilgo, 1990; Odom & Chandler, 1990). The caregiving responsibilities that parents assume after taking the child home from the hospital go beyond those for which they have planned (Hanline & Deppe, 1990). Parents and caregivers

now must deal with the emotional impact of having a child with special needs. Medical terms and jargon such as "related services" or "early intervention" are thrown at them while school needs (in the traditional sense) automatically assume a much lower priority and, in some cases, are eliminated from the discharge plan.

It is difficult for families to accept the news that their child has a chronic illness which will require ongoing medical attention for all or a portion of their lives. Much of the time this new diagnosis is all that the family will hear in a sitting; they tune out all of the other information provided. It is important that the family have at least one professional within an agency with whom trust can be built. When two or more professionals in a hospital have problems communicating their views concerning the needs of a child, the family will leave the hospital without the most beneficial program to pass on to the receiving agency. Families have reported that the successful transition from a dependent relationship within a health care setting to the independent role expected within the community care setting requires careful preparation and planning (Bruder & Walker, 1990; Hains, Rosenkoetter, & Fowler, 1991). The Transition Liaison would provide the family a feeling of much-needed confidence to ask questions they might otherwise feel awkward asking. The Transition Liaison would also reduce any perception the family may have about getting the "run around" from so many different professionals.

Upon discharge, the Transition Liaison would coordinate services for the family back into the home. A professional who has contact with parents prior to

discharge and who provides follow-up services in the home can assist parents in feeling confident when caring for their child. If support to families can begin at discharge, and continue with follow-up services in the home, the family and the child would benefit from uninterrupted support from all professionals (Hanline & Deppe 1990). This support may involve early intervention services for an infant, which may be home-based or agency-based. The early intervention services would be arranged in the hospital, and then transferred to a case manager assigned by the receiving community agency.

Some professionals feel uncomfortable with behavioral, developmental, or school problems, but improved education, and the development of better models of collaboration and communication will result in a larger proportion of physicians who can interact meaningfully on school and services issues (Levine, 1982). When a child begins school or returns to school, information about his needs (e.g., special precautions, treatments, or other care needs) must be provided. If these needs are not specified, the sending agency has not equipped the school properly. Parents and professionals must realize that upon returning to school, teachers and school administrators are now just as important as the physician was in the hospital. Conversely, the school system must provide relevant information to the hospital staff when a child re-enters the hospital. A Transition Liaison would make this process much more efficient and logical by collecting the pertinent information and seeing that it gets distributed to the appropriate agencies.

Professionals must also take care to support, but not supplant the family's role (Shelton, Jeppson & Johnson, 1987). A parental role in the transition process can take on many different forms. The parents must be an integral part of the intervention team for their child and be knowledgeable about their rights as parents of a child with special needs. Being a full team member and facilitating communication between and within agencies is extremely important in making a smooth transition between programs. Developmental specialists depend on parents for family input into the program and a deeper blending of developmental intervention and home interactions (Gilkerson, 1990). Parents must also serve as teachers in order to foster the skills a child needs to survive in a new environment. They often take their child to the new classroom and get acquainted with the classroom teacher and other students before entering (Hains, Fowler, & Chandler, 1988). This may also help a child adjust after a long hospital stay.

Coordination of school re-entry within the child's school district for school-aged children (and any related services of special education that the child may need) can be an invaluable service for parents. Often, parents feel as though they are caught in the middle of the hospital and the educational agency. They are not sure of how to effectively communicate the medical need of the child to an educational setting. Unfortunately, there are times when an adversarial relationship between the pediatrician and the school is an unavoidable result (Levine, 1982). Levine has also stated that sometimes the medical model of

disease cannot be applied effectively to school-related problems and developmental dysfunction. The role of a Transition Liaison as facilitator of a school re-entry service could attempt to smooth the historically inharmonious relationship between hospitals and schools. The Transition Liaison could also provide information to the parents concerning rights for the child and the family, if identified or necessary. If a school-aged child needs another hospitalization at a later time, the communication (transition) system is already in place to coordinate needed devices for re-entry into the hospital with minimal interruption in the child's educational program.

Teachers and administrators can also help to ease the transition process. Professionals in the school system must begin with a positive attitude about working with children with special health care needs (Hains, Fowler & Chandler, 1988). They must be willing to learn new procedures and to adjust their typical routines to meet these special needs. The attitudes taken by these professionals will serve as models for the child's peers in the classroom. Communication with other students, parents and continued communication with the hospital is important in case future hospitalizations become necessary. In some instances, the physician may request input from the classroom teacher concerning the child's classroom behavior. In the case of re-entry to the hospital, the teacher should be able to devise a system so that the child will not fall too far behind classroom peers in school work. The Transition Liaison would be the major link between the educational community and the hospital setting. The Transition Liaison could

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perform in both settings without appearing as a threat to either agency, while helping the most important individual needing the services, the child.

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Discharge Planning Model

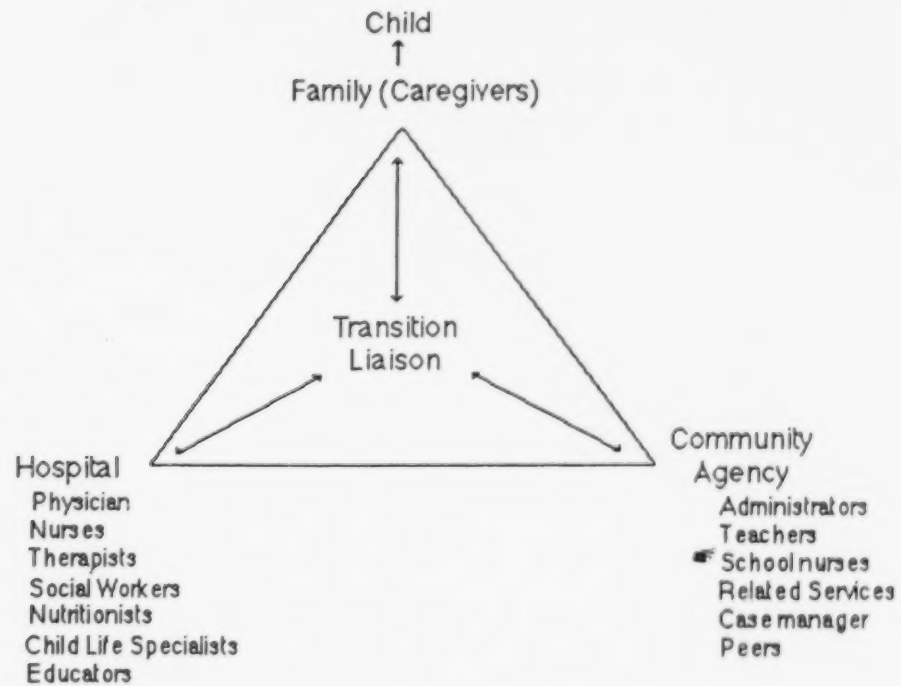


Figure 1. Discharge Planning Model showing the pivotal position of the Transition Liaison.